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ABSTRACT

This document presents one module in a set of training resources for trainers to use with parents and/or professionals serving children with disabilities; focus is on training for professionals working with families. The modules stress content and activities that build skills and offer resources to promote parent-professional collaboration. Each training module takes about 2 hours and has eight sections: a publicity flyer, topic narrative, overview, trainer agenda, activities, summary, bibliography, and evaluation. Introductory information explains how to use the modules including conducting a needs assessment, planning the training, selecting the training module, implementation, evaluation, and followup. Objectives of this module are: (1) gain an understanding of emotional issues and stresses in a family that has a child with a disability, (2) understand the stages of the coping process, (3) identify the similarities between parents and professionals, and (4) explore parent and professional differences. A bibliography identifies six books, magazines, or other resources. (DB)

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TRAINING for PROFESSIONALS WORKING with FAMILIES

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California State Department of Education,
Special Education Division
Program, Curriculum and Training Unit

Presents a Module on:

Training for Professionals Working with Families

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Revised by:

Lynn Carlisle

Pat Lesniak

1988

This module, as well as thirteen others, were produced under the direction of Karl E. Murray and Susan Westaby of the Program, Curriculum and Training Unit, Special Education Division, CA State Department of Education. The modules are being field-tested throughout 1988. During this field-test stage, they are available by sending $ 5.00 for each module (includes tax and mailing) to: Parent Training Modules, CA State Department of Education, P.O. Box 944272 - Room 621B, Sacramento, CA 94244-2720. Make checks payable to Parent Training Modules.

INTRODUCTION

The Parent/Professional Training Modules have been developed to serve as a core set of training resources for trainers to use primarily with groups of parents. Some of the trainings were designed specifically for combined groups of parents and professionals, and all the trainings can be adapted for use with parents or professionals as separate or combined audiences. The training modules in the series focus on content and activities that build skills and offer resources to promote parent-professional collaboration to ensure quality education for all students with disabilities. There are fourteen training modules in this series:

Parent Professional Collaboration
Parental Involvement
Stress and Support in the Family
Coping with Loss and Change
Parent Support Groups
An Effective Community Advisory Committee
Community Advisory Committee Leadership Training
Communication Skills
The Individualized Education Program: Rights and Responsibilities
Placement in the Least Restrictive Environment
Training for Professionals Working with Families
Parent Professional Collaboration in Planning for Employment
Transition Planning
Interagency Collaboration: The Parents' Role

Each training module has eight sections:

Flyer
Topic Narrative
Overview
Trainer Agenda
Activities
Summary
Bibliography
Evaluation

Within each of these sections there are these materials:

Flyer - The Flyer highlights what participants can expect to learn by attending the training. It can be personalized for each training by adding date, time, and location in the appropriate spaces.

Topic Narrative -- The Topic Narrative contains content information specifically for the trainer. Trainers use the information to enhance their knowledge and understanding of the subject matter of the training module.

Overview -- The Overview contains the goals and objectives for the module; and the content and presentation strategy for each activity contained within the module.

Trainer Agenda -- The Trainer Agenda contains details of trainer and participant activities, materials and media. It is a suggested agenda that trainers can personalize to fit their style and the specific needs of the participants. A few modules that deal with sensitive or difficult content have Trainer Tips included in the Agenda section.

Summary -- The Summary contains highlights of all the content information presented in activities within the training. The Summary was designed to provide information to prospective participants and to workshop planners.

Bibliography -- The Bibliography contains the names of books, magazines and other resources that were used as references in developing the training modules and may serve as a list of suggested reading materials for trainers as well as participants.

Evaluation -- The Evaluation contains questions that directly assess the objectives of the module as well as some general questions to evaluate the usefulness of materials and trainer effectiveness.

The Parent/Professional Training Modules have been designed to be a flexible and expandable resource for trainers of parents and professionals. It can be housed in binders or in file folders and rearranged as needed. Trainers are urged to add articles, resources and other materials that will make each training reflect their individual style and meet the needs of the participants.

HOW TO USE THESE TRAINING MODULES

Conduct a Needs Assessment:

Gather as much information as you can about the groups that you will be working with. The following types of questions may help:

Does the group meet regularly or is it assembled specifically for the purpose of this training?

What does the group want to accomplish? Does it have a stated goal? Are there a set of outcomes that the group wants to achieve?

Who is involved in the group (agencies and organizations)?

If the group is an ongoing group, how is the group organized? (officers, executive committee, standing committees, task groups, etc.)

What has the group already done? What training has the group already received?

What is the group working on now?

How does the group get things done?

Has the group conducted a needs assessment to determine the group's need for training and the training topics of interest?

Plan the Training

Typically, this is a dialogue between the trainer and the client. Often, the client will have a specific topic or activity in mind. Sometimes additional topics will be suggested during the needs assessment process when the trainer probes to get more information. The trainer can share a list of module topics and/or several module summaries to aid the client in selection of a topic(s) from the series.

Select the Training Module

The Parent/Professional Training Modules offer a wide selection of topics and activities. The trainer can select the module that deals with the topic chosen by the client.

Review the Training Module

The module provides the core activities and a suggested trainer agenda. The trainer can adjust both to reflect their individual style and the needs of the client.

Identify Additional Resource Materials

The trainer can add articles, resources, and other materials to the core training module. Often a trainer will introduce local resources or pertinent sample materials.

Deliver the Training

The Parent/Professional Training Modules are best delivered by a training team of a parent and a professional. Collaboration is modeled by the team as each member of the team displays unique perspectives, abilities and knowledge as they enhance each others presentation styles.

Evaluate the Training

Evaluation is an essential element of any training. Each module includes an evaluation that assesses the specific objectives of the module and the usefulness of materials. These evaluations can assist the trainer in refining the module content and modifying presentation style, if needed.

"Follow-Up" the Training

It is a good practice to follow-up any training with a personal visit, letter, or a phone call. The trainer may wish to keep a list of names, addresses, and phone numbers of participants to facilitate follow-up. The follow-up usually consists of discussion about how the training may have impacted the client's personal or professional life. Clients may express the desire for further training and/or materials and resources.

Training for Professionals Working With Families

(For All Interested and Involved Professionals)

You, as a participant, will learn about:

- the emotional issues and stresses of a family with a child with a disability
- states of the coping process
- similarities between parents and professionals
- basic differences between parents and professionals

Day and Date:

Time:

Location:

For More Information, Call:

Please Come

Training for Professionals Working with Families

Topic Narrative

Families, and especially parents, are considered key factors in their children's growth and development. Educational research is pointing to the fact that when parents are involved in their children's schooling, the children are more likely to achieve at a higher level (Henderson, 1981). Public Law 94-142 has mandated that parents be given the opportunity to be equal partners in planning their child's education program.

Many professionals are enthusiastic about parental involvement in particular programs. There is a growing trend, especially in education, for parents and professionals to collaborate as partners in reaching goals for children.

Children with special needs often have many more areas of development outside of education which require much time and special services. Parental involvement can be many faceted by the time children reach school age. The family structure can be very delicately balanced, as parents try to meet the complex needs of the child with a disability, the needs of the rest of the family, and their own needs.

Professionals providing needed services to children will probably be in the proactive position of inviting parents to be active in their program or treatment. The most satisfying relationship between parents and professionals, and the one which most benefits the child, is one of partnership and collaboration. But, as with most things in life, the achievement of the "best" requires effort, understanding and a willingness to accept and even instigate change.

To be collaborative and to build partnerships, parents and professionals need to be able to give and take, walk in each others shoes and exchange leadership as the situation requires. They need to be able to support each other where their roles are distinct.

This is a requirement from both parties, but because of the professional's "expert" position, he may most often be in the position to initiate the relationship and bear the major responsibility for developing positive working relationships. With some families this will be an easy and natural process. With others, there will be difficulties.

In order to establish a basis from which a partnership with parents can grow, professionals need to have a working knowledge of the unique needs of families of individuals with special needs.

- Professionals need to gain an understanding of the emotional issues and stresses of a family - the impact of a child with special needs on the entire family over an extended period of time. Parents often do not share this overwhelming body of knowledge and feelings with each professional who works with their child yet it is vital to the relationship that the professional have this understanding.

- Professionals need to be conversant with the states of the coping cycle and realize that this is a lifelong growth process for the family.

- In order to build bridges of understanding, it is helpful for professionals to identify the attitudes, hopes, and fears that they hold in common with the parents with whom they will be working.

- A vital part of building a working partnership is recognizing that each one of us perceives and interprets the world differently. We each accept these perceptions and our interpretations of them as right. Often our subjective feelings are not clear to us. Parents and professionals may have greatly differing perspectives and goals for a child. It may be very difficult to share and understand these different perspectives and find ways of working together for the same goals. It is important for the child and other family members to see how parents and professionals function as a team.

Overview

The goal of this module is to increase knowledge and understanding of the unique needs of families of children with disabilities in order to enhance parent professional collaboration.

Objectives

1. Gain an understanding of emotional issues and stresses in a family that has a child with a disability.
2. Understand the states of the coping process.
3. Identify the similarities between parents and professionals.
4. Explore parent and professional differences.

Objective Number	Suggested Minutes	Content	Presentation Strategy
	10	Introduction, Objectives and Agenda Review	
1	10	Warm-Up/Inclusion Activity	Individual Sharing with Group
1	40	Sculpting a Family	Small Group Role Play with Large Group Observation and Large Group Discussion
2	25	Coping Process	Lecturette
	10	Break	
3	20	Similarities Between Parents and Professionals	Large Group Activity
4	30	Differences Between Parents and Professionals	Lecturette and Large Group Discussion
	10	Conclusion and Evaluation	
	155		

Suggested Trainer Agenda

WORKSHOP TITLE: Training for Professionals Working with Families

DATE: _____ PAGE: 1

PRESENTERS: _____

CLIENT: _____

GOAL: To increase knowledge and understanding of the unique needs of families of children with disabilities in order to enhance parent professional collaboration.

OBJECTIVES:

1. Gain an understanding of emotional issues and stresses in a family that has a child with a disability.
2. Understand the states of the coping process.
3. Identify the similarities between parents and professionals.
4. Explore parent and professional differences.

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS MEDIA
10 minutes		Welcome Introductions Objectives and Agenda Review Display Objectives and Agenda on Chart Paper	Listen	Chart Paper Pens Tape Chart of Objectives and Agenda
10 minutes		Warm up/Inclusion Activity Trainer instructs participants to give their names and current professional role. Participants are then asked to complete the following statement by naming a strength or positive strategy that they bring to a parent-professional relationship. "When I am working with a parent, I ..... " Participants may choose to pass.	Participate or pass	

Suggested Trainer Agenda (continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS
40 minutes		<u>Sculpting a Family</u> Activity/Handout 1 Small Group Role Play with Large Group Observation and Large Group Discussion Distribute Handout 1 at end of activity "Sculpting a Family" is an activity designed to draw helping professionals into a closer relationship with a hypothetical family by helping them gain an understanding of emotional issues and stresses of a family who has a child with a disability. The trainer will conduct Activity 1 which has specific directions. Allow 20 minutes for this part of the activity. After the activity is completed the debriefing session follows. The trainer should allow 20 minutes for participants to debrief as follows: o ask the role players how they felt during the activity; encourage them to elaborate on their feelings as new blocks were given to them, o ask the other participants for their reactions to the role play, and how they felt as they were given the blocks at the end, o close the activity by restating the purpose and distributing Handout 1.	Four role players actively participate. The remainder of the group sit in a circle around the role players and observe. Discuss, question, comment.	Handout 1
25 minutes		<u>Coping Process</u> Activity /Handout 2A, 2B, 2C Lecturette Distribute Handout 2A Trainer will deliver lecturette on the grieving and coping process. Participants will refer to Handout 2A as Trainer talks about work of Dr. Ken Moses. The Trainer may wish to prepare a wall chart as follows	Listen, question, comment, share experiences.	Handout 2A Chart

Suggested Trainer Agenda (continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS
		to guide the lecturette: Grieving / Coping Denial — Contain the Effects of the Disability Anxiety — Devalue Physique Guilt — Enlarge Scope of Values Anger — Minimize Issues of Comparison and Depression — Competition After the lecturette is complete, distribute Handout 2B and 2C. Handout 2B discusses some guidelines for professionals to consider when engaged in a sharing process with parents. Handout 2C illustrates another model for understanding the grieving and coping process.		Handouts 2B, 2C
10 minutes		Break		
20 minutes		Similarities Between Parents and Professionals Activity/Handout 3 Large Group Activity Display Charts Distribute Handout 3 at end of activity For the activity the Trainer(s) will need to prepare 3 chart papers: the 1st will read "When I'm meeting with parents I feel ..." the 2nd will read "I wish parents were more ..." the 3rd will read "I like it when parents ..." The large group will be asked to finish the sentences with a single word or short phrase, in a brainstorming fashion. Encourage participants to be candid in their thoughts. The Trainer will record responses on the chart. Take 3 minutes for each chart. Post all 3 charts and use them as a basis for discussion. Distribute Handout 3	Contribute ideas. Participate in Discussion.	Charts Handout 3

Suggested Trainer Agenda (continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS
		and have the participants look particularly at the lists generated by parents. Elaborate on the idea that professionals and parents experience the same or similar feelings when they work together. A real partnership can begin to develop when they acknowledge and share their feelings.		
30 minutes		<u>Differences Between Parents and Professionals</u> Activity/Handout 4 Lecturette and Large Group Discussion Distribute Handout 4 Trainer will deliver lecturette based on Handout 4. Handout 4 lists some basic differences that may occur between parents and professionals. The differences are to be used as a point of reference for discussions. They are not meant to be stereotypical. They are meant to represent the **extreme** point of view. Use the following examples to stimulate discussion: Individual vs. Group All parents want their child to be treated like a special, prized person, not just part of a group. Teachers must consider that each child is a member of the group and consider individual needs in terms of what is best for the group. Emerging Skills vs. Established Skills Parents are delighted when Johnny gets his first reading book and is learning to read. Teachers are aware that Johnny must complete 3 more books and learn a whole sequence of skills to meet his IEP objective. History vs. Present Parents can see a child's past with perfect clarity. They know how much the child has progressed. In contrast professionals deal with	Listen, Discuss	Handout 4

Suggested Trainer Agenda (continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS
		the here and now. They review history but don't dwell on it. Professionals tend to look beyond. Present vs. Futuristic Professionals use the term "Transitions" to talk about a whole continuum of education that culminates in lifework or employment. The parents of a toddler with a disability or a 10 year old who can't read are not looking very far into the future. Diffused vs. Specificity Parents don't separate a child into affective, cognitive, social, or emotional pieces. Parents see the whole child and how that child affects the family. Professionals, because of areas of specialization and training, concentrate on their areas of expertise, i.e., reading, speech, sensorimotor. Emotional vs. Objective Parents are emotionally involved with their children, and it's very difficult to be objective. Professionals are trained to be objective and to observe behaviors without personal feelings. This area becomes one of great concern when parents want to develop warm and caring relationships with professionals. Given vs. Achieved/Chosen Professions Parents normally do not choose to have a child with a disability. Professionals choose to enter a profession to serve children with disabilities and/or their families. Submissive vs. Dominant Professionals have earned degrees and diplomas that show they are "experts". Professionals, because of this knowledge in a specific subject area, tend to dominate the parent/professional relationship. Parents may feel "less than".		

Suggested Trainer Agenda (continued)

TIME	WHO	TRAINER ACTIVITIES/CONTENT	PARTICIPANT ACTIVITIES	HANDOUTS
		Individualized vs. Universal Parents want an individualized education for their child - an education that will meet all the child's needs. While professionals strive to provide each child with such an individualized education, they must also provide an atmosphere of global instruction that is structured and behavioristic.		
10 minutes		<u>Conclusion</u> Restate objectives. Thank Participants. Complete Evaluation/Handout 5.	Complete Evaluation	Handout 5

Professionals Working with Families
Activity/Handout 1, Page 1
Small Group Role Play with Large Group Observation and Large Group Discussion
40 minutes

Sculpting a Family

Materials Needed:

25 rather large wooden blocks of varied sizes and shapes
role play cards for each of the players
name tags for each of the players

Directions:

Select four members of the group to be involved in the role play and explain that the activity is designed to give people a picture of what it might be like to have a child with a handicapping condition. Explain the directions to each person as stated on the role play cards for each role. You may also need to show them how they are to hold hands with one another. Let them know that you will be telling a story about them as they move about the circle, and that you would like them to try and express their feelings about their role as they listen to the story. Be sure to answer any questions they might have, but avoid actually discussing the script so that they can experience the activity as part of the group. Give each one a name tag with whatever name they would like to use in the role play.

In preparation for the activity, have the audience set their chairs in a circle or semicircle with a wide enough space in the middle for the role players to move about, but not to spread out. If there are two trainers, one should act as the narrator and one should hand the players blocks at the appropriate times. A person from the group can also be asked to serve as the one who hands out the blocks.

Before you begin the actual narration, explain to the participants that this activity is designed to give them a look at what it might be like for a family with a young child with special needs.

This activity was adapted by Sheila Wolfe from the *Role of social services in serving families of children with handicapping conditions: A training manual for social service workers.* Marilyn Bartlett, Judith Rothchild, Linda Kjerland and Ruth Dropkin. New York University, Resource Access Project (RAP) - Region II, School of Continuing Education, 3 Washington Square Village, Suite 1-M, New York, NY 10012

Cue Card - Husband/Father

When you are introduced, come into the circle and join hands with your wife. Hold each other's RIGHT hands and keep them raised above your heads. Walk about the circle at a mutually comfortable pace. Keep your RIGHT hand raised and extend your LEFT hand to receive and hold blocks as they are given to you.

Cue Card - Wife/Mother

When you are introduced, come into the circle and join hands with your husband. Hold each other's RIGHT hands and keep them raised above your heads. Walk about the circle at a mutually comfortable pace. Keep your RIGHT hand raised and extend your LEFT hand to receive and hold blocks as they are given to you.

Cue Card - Daughter/Sister

When you are introduced, come into the circle and place your RIGHT hand on top of those of your parents. Remember to keep your RIGHT hand raised above your head with your parents, and extend your LEFT hand to receive and hold blocks as they are given to you.

Cue Card - Son/Brother

When you are introduced, come into the circle and join RIGHT hands with your parents and sister. You are playing the role of a child with a handicapping condition, so your appearance or actions might suggest that to the audience. Place yourself between your father and mother as you join hands. Remember to keep your RIGHT hand raised above your head with your parents and sister and to keep your LEFT hand extended to receive and hold blocks as they are given to you.

Sculpting a Family

Narration

1. As we begin this session I'd like you to meet a family. (Gesture to each person involved in the role play as you introduce them). Let's first get to know _____ (name of wife and mother) and _____ (name of husband and father) as they come into our circle.

2. In the beginning, life was relatively uncomplicated. There was plenty of time for getting to know each other and for sharing ideas and dreams. When you were married you worked together to establish a home and a lifestyle together. During the 3rd year of your marriage you happily announced the welcome news that you were going to have a baby.

3. (Wife) and (husband), you and your families and friends all made great preparations in joyful anticipation of the "blessed event".

4. The pregnancy and delivery went well and you proudly announced the arrival of your daughter _____. (Gesture to sibling and welcome into circle). Everyone was elated and shared your happiness. There were parties, presents and great wishes for this wonderful child and family.

5. After about 2 years, you decide to have another baby - 2 children and you'll be the "typical American family". Friends say you'll probably want a boy, but you respond, "Oh, it really doesn't matter as long as it's healthy".

6. Your baby son is born ... but this time it is a long difficult delivery. Instead of the smiling faces of family and friends, you are surrounded with the concerned looks of doctors and nurses. They avoid your questions and there is hushed talking in the corridor outside your hospital room. Here is a symbol for the chill that is beginning to take over your hearts. (Give a block to mother and father.)

7. Your baby is having problems, and after what seems to be an eternity you are told that he is not "normal". (Gesture to new sibling to join family). Friends and family don't know how to respond - to offer congratulations or condolences. There are no parties. Here is a symbol for the shock and isolation you felt. (Give mother and father a block.)

8. Remember what you dreamed your new baby would be like? Now you realize that your dream of the perfect child is shattered. Now you don't know what to expect. (Daughter), you too had ideas about your new little brother. Everyone seemed so happy before he was born, but now ... here is a symbol for your sadness, anger, and confusion. (Give mother, father, and daughter each a block.)

9. Your family now has a child with special needs and you will all go through many changes in lifestyles and values. As you try to adjust to these changes there will be rough times, unbearable times, as well as times of hope and pleasure. Here is a symbol of adjustments that each of you will make. (Give father, mother, sister a block).

10. You have so many needs, so many questions, and so few answers. Here is a symbol for the search for answers and services. (Give father and mother a block.)

11. (Mother), it didn't take long for you to learn about attitudes towards children with disabilities and their families. Remember how you felt presenting (daughter) to the world. This time with (son), the world seems to have changed -- or have you? Here's a symbol for the awkwardness and turbulence that you feel. (Give mother a block.)

12. (Father), people don't seem to notice that you are upset, too. The doctor's visits, the Regional Center evaluations, the home visits by the early intervention people are all scheduled when you are at work. All the special things for son are happening while you are trying to earn a living for your family and pay for all the extras for son. Here is a symbol for your worry and your hurt for loss of involvement. (Give father a block.)

13. (Mother), you planned to return to work after the second baby, but (son) takes so much attention, so much work, so much planning. You couldn't work even if you wanted to. Who would take (son) to the doctor, therapy, infant program, be home for home visits. Besides, what would the professionals think? It's impossible to find child care. Here's a reminder of all the people you need to see and things you need to do. (Give mother a block.)

14. (Daughter), since your brother was born, a great deal has been expected of you. You understand that he needs lots of attention and time, but you need some too. Now your parents seem tired, shorttempered, and Mom cries a lot. Your friends want to know what's wrong and why doesn't your Mom ever come to your school instead of your brother's all the time? It seems no one wants to come to your house to play. (Daughter), here is a symbol of all the things you have to try to understand. (Give daughter a block.)

15. (Son), it seems as if you're always being taken to see another strange person. Sometimes it's scary, especially when they take you away from Mom and Dad. Besides, they keep making you do the same things over and over. Don't they know you put pegs in holes yesterday? Why is everyone always looking at you? Sometimes you feel bad about (sister) and taking so much attention away from her. Here is a symbol for your feelings. (Give son a block.)

16. (Mother and Father), you have so little time for each other and it is so easy to argue. You've been told there are support groups, but who has time to go to them. You are so worried about the future and feeling so lonely. This block symbolizes all the worries and fears that you sometimes are unable to share with each other. (Give father and mother a block.)

17. Family, after awhile you settle into a more comfortable routine. (Son) is making progress in the infant program, you've made friends with some of the parents from the support group you've joined. You've even figured out how to make some of (son's) therapy into games that (daughter) can play with him. Then, the letter comes saying that services are being reduced. Here is a symbol of the anxiety and the letters and phone calls and meetings you'll need to go to in order to keep things going. (Give block to mother and father.)

18. Wait, what's this ... now it's time for (son) to go into a preschool program? A new program ... another parent group .... more evaluations? They say that (son) can be served by the school district now that he's three. The people from the infant group will help make the transition, but they say to talk with the Regional Center counselor. The Regional Center counselor says to talk with the special education department at the school district. The special education people say call the child care referral service to find a mainstream preschool and then they'll see if they can work out something. The doctor wants to know why the school needs another copy of (son's)

medical records. Here's a symbol of the changes that each of you will have to make. (Give each family member a block.)

19. Family, let's stop now and share some of your blocks with the people around you. (Role players give blocks to audience.)

Debrief

1. Ask the role players first how they felt during the activity. Encourage them to elaborate on their feelings as new blocks were given to them.

2. Ask observers for their reactions to this activity.

3. Close the activity by restating the purpose of the activity.

Coping Process

When parents await the birth of a child, they dream about who the child will be and what s/he will be for them. The wait for a wanted child stirs deep feelings of a personal and primitive nature. Dreams are born before the child is born.

When a child is born with disabilities, or when these disabilities are finally recognized, usually these dreams are shattered and the grieving process begins.

To begin new dreams about their child, the parents must begin a healing process. The grieving process is the healing process..

The grieving process is natural.

The grieving process is necessary in order to separate from lost dreams.

The loss that parents experience is so deep and personal that most parents feel totally isolated and unaware of what is happening to them. The grieving process is elusive and liquid, and it is difficult to share feelings even with a spouse.

Dr. Ken Moses talks about **grieving** and **coping**.

Grieving

Grieving is an emotional process. The feeling states include:

denial
anxiety
guilt
anger
depression

The feeling states:

are spontaneous,
have no specific order,
can be felt simultaneously,
appear to be cross-cultural,
and reoccur in different contexts.

One cannot grieve alone. Successful grieving seems to be dependent upon interactions with other people.

Unfortunately, the emotions felt and displayed by the grieving person are often not accepted by himself or those around him. Even "supportive" professionals can be frustrated by the behavior and the process. Labels and expressions of disapproval are often given.

Few of the people who wish to help are aware that each feeling or state serves a useful and necessary purpose. Each state serves to separate the parent from the lost dream, so that slowly, new dreams are dreamed.

Denial keeps the parent from being totally overwhelmed. It protects him until he can gather inner resources and external supports. This is a period of survival. Denial is the feeling state identified by professionals as being the most frustrating and destructive.

Anxiety is often experienced by parents of children with disabilities. This anxiety appears to be related to the important balance between responsibility for the welfare of their child and the right to have an independent life of one's own. Having a child with a disability disrupts this balance. New pressures and responsibilities are piled on the already existing pressures and responsibilities of the lives they led prior to the birth of their child with a disability. This pressure often provokes anxiety.

Guilt is a vehicle which helps parents reevaluate their ideas about their impact and control over their lives and the world around them, about their religious beliefs, about ethics. They can struggle with the cause of things, explore the "whys". It is a very painful process, and it is difficult for many professionals to accept that such a debilitating feeling state can have positive effects.

Anger and even rage is felt by parents of impaired children. It is perhaps the most frightening of all feelings, since most of us have been taught anger is inappropriate to express in almost all social situations. The anger may be directed at the child, the professional, spouse, God, science. It is important at this point to distinguish between the concept of anger expression and the "acting out" of anger. Parents who ventilate with significant others are less likely to act it out.

Anger is a vehicle that helps parents to question their concept of justice. As they react against the injustice in their lives, they can restructure their ideas about seemingly unfair events from which none of us can escape.

Depression gives parents an opportunity to review their competence. People who are depressed often view themselves as weak, useless, or worthless. It is a depressing event for a parent to know that he cannot "fix" his child, and that there is little he can do to make him "normal".

However, a parent can redefine his competence in the world around him, let go of old ways of judging himself, and allow himself to be an ordinary person.

Coping

Through the states of grieving parents are learning to cope with their loss and their new situation. "Coping" covers most of the remaining activities that parents experience in their separation and growth process. The coping process includes:

Containing the effects of the disability: The parent does not let the effects of their child's disability encroach on the functions that are not affected. Their child is a child first of all, who happens to have a disability. For example, they don't have a Down's child. They have a baby who happens to have Down's Syndrome.

Devaluing physique: Western culture, especially, places a high value on physical appearance. Often people are judged on appearance. Different behaviors, speech, gait, mannerisms, physiques are often viewed negatively. Valuing differences and devaluing physique deals with this issue.

Enlarging one's scope of values: Most people tend to narrow their values, interests, and associations as they grow older. People seem to become set in their ways or rigid in their thinking. In order to really accept their child, parents must enlarge the scope of things that they value and increase their understanding. They must genuinely value the lifestyle their child may choose. Parents have to relook at what they believe to be "the good life".

Minimizing issues of comparison and competition: A comparative or competitive atmosphere can be devastating to impaired individuals and their families. How one compares with others is far less important than the mastering of a skill or demonstration of competency. To cope with a child's disability, parents come to value the child and respect new achievements without making comparisons. First and foremost parents learn to appreciate the child.

Guidelines for the Sharing Process between Parents and Professionals

1. Always be aware of the dynamics of grieving; it is easy to forget the process of grief when faced with intense emotion.

2. Review your own personal strengths and weaknesses around grieving over past significant losses of your own.

3. Clarify and practice focusing on the differences between a feeling and an action. Many actions can be immoral, illegal, unethical, insensitive, and inhumane; feelings are part of being human, crucial to dealing with loss, and therefore, should not be judged or criticized.

4. Try to avoid answering direct questions that are of a general or predictive nature, because parents are usually more interested in having their concerns heard than in getting answers.

5. Try to remember you are not totally responsible for correcting the child's disability, nor the trauma that the disability brings to the family. Limit your concerns to the areas that fall within your professional role.

6. Try to separate the factual statements from the feeling statements that are both received and sent by you. It helps to maintain consistency in the types of communication between parents and school people.

7. During all your interactions do not ignore or abandon your professional convictions, recommendations, or program guidelines; the direct educational services offered the child are always the first priority.

** Note: One cannot grieve alone. Successful grieving appears to be dependent upon supportive human interactions.

Adapted from the Chapter entitled: *The impact of initial diagnosis: Mobilizing family resources* by Kenneth L. Moses, which is included in the book: Parent professional partnerships in developmental disability services.

Complete reference: Mulick, J. A. and Pueschel, S.M., eds. *Parent professional partnerships in developmental disability services.* Cambridge, MA: Academic Guild Publishers, 1983.

STATES OF THE COPING PROCESS: A FRAMEWORK FOR UNDERSTANDING

Bridging the Parent Professional Communication Gap

Did you know that when professionals have meetings with parents that they feel "frustrated, angry, guilty, and helpless"? This was documented at the 1979 IOWA ACLD CONFERENCE WORKSHOP where a group of approximately ten parents and fifteen professionals were separated (with all the parents together, and all the professionals together) into two groups and were asked separately to list their feelings during meetings with parents (in the professional group) and with professionals (in the parent group). These are the lists each group generated:

Parent Group List

"When I'm meeting with professionals, I feel ..."

a desire for honesty
run around
don't know too damn much
frustrated by jargon
anger
disgust
disappointed
defeated
guilt, guilt, guilt
overwhelmed
good
unsuccessful
trustful
respectful
sympathy
defensive
threatened

"I wish professionals were more ... "

helpful
child-oriented
concerned
knowledgeable
receptive to profession upgrading
humanistic
understanding
free to be open

"I like it when professionals ... "

contact/communicate
listen to me
come with positive information
show respect for students

become involved in support groups
respect the knowledge of parents
individualize for students
share information
share professional knowledge
treat parents as equals

Professional Group List

"When I 'm meeting with parents I feel .... "

frustrated
professional liability
parents don't care
parents not very informed
uptight
threatened
insecure
pressured
patronized
tired, burned out
tense
upset
unsure
incapable of dealing with parents
unprepared
indignant
put down
successful
organized
confident
satisfied
knowledgeable
helpful
appreciative
fulfilled
accomplished
good about myself
needed
burdened with red tape

"I wish parents were more ... "

attentive listeners
informed
assertive
interested
less intimidated
reliable
initiating in dealing with problems
responsible

caring
involved
supportive
objective
appropriate role models
sensitive

"I like it when parents .... "

ARE PERFECT
attend conferences, staffings ....
follow through with suggestions
both attend meetings
see progress
provide feedback regarding the child's "performance"
are supportive of special services
are open with their communication
put their child's education first
show initiative in finding out what their child does in school
remember me at Christmas
are honest
are objective
are understanding of professional perspectives
are open minded

Professionals Working with Families
Activity/Handout 4
Lecturette and Large Group
Discussion
30 minutes

Parent/Professional Differences

Parent	Professional
Individual Concern with one child's individual progress, needs	**Group** Must focus on the whole class or group
Emerging Skills Concern with what child is learning	**Established Skills** Knowledge or what child has mastered
History Has the perspective of how far the child has come	**Present** Concern with present development of child
Present Concern with the here and now	**Futuristic** Look to what child will be able to do in the future, career potential
Diffused Tend to see whole child's on-going development	**Specificity** Concern with specific aspects of the child
Emotional Emotional involvement with child, primary relationship	**Objective** Sees child more objectively, able to distance self from child
Given Given this child , parents must accept the child as is	**Achieved/Chosen Profession** Professional career choice
Submissive Parents often feel helpless, uneducated	**Dominant** Teachers have the power, position, expertise
Individualized Want to have their child approached and taught as an individual to meet his or her needs	**Universal** Look for one best method, way to work with all children

Adapted from: Parents and professionals advocating collaborative training (P-PACT), San Diego State University, Department of Special Education,1987.

Training for Professionals Working With Families

Summary

Families, and especially parents, are considered key factors in their children's growth and development. P. L. 94-142 has mandated that parents be given the opportunity to be equal partners in planning their children's educational program.

There is a growing trend, especially in education, for parents and professionals to collaborate as partners in reaching goals for children.

The family structure can be very delicately balanced, as parents try to meet the complex needs of the child with a disability, the needs of the rest of the family, and their own needs.

As professionals providing needed services to children you will probably be in the proactive position of inviting parents to be active in your program or treatment.

The most satisfying relationship between parents and professionals, and the one which will most benefit the children, is one of partnership and collaboration.

To be collaborative and to build partnerships, parents and professionals need to be able to give and take, walk in each others shoes, and exchange leadership as the situation requires. They need to be able to support each other when their roles are distinct.

In order to establish a basis from which a partnership with parents can grow, professionals need to have a working knowledge of the unique needs of families of individuals with special needs.

Professionals need to gain an understanding of the emotional issues and stresses of a family.

Professionals need to be conversant with the states of the coping cycle and realize that this is a lifelong growth process for the family.

In order to build bridges of understanding it is helpful for professionals to identify the attitudes, hopes and fears that they hold in common with the parents with whom they will be working.

A vital part of building a working partnership is recognizing the differences inherent in the roles of professionals and parents.

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Evaluation

Your responses to the questions/statements below will assist us in improving this module. Please respond to all items. Your participation in this evaluation is completely anonymous. DO NOT place your name anywhere on the evaluation.

Based on a scale of 1 through 10, how much of the information presented was new to you?

_____ 1 is not much new; 10 all new

	Strongly Disagree	Disagree	Undecided	Agree	Strongly Agree
1. As a result of this session, I have an increased understanding of the emotional issues and stresses of a family that has a child with a disability.	1	2	3	4	5
2. As a result of this session, I am aware of the grieving and coping process.	1	2	3	4	5
3. This session helped me to understand the states of the coping process.	1	2	3	4	5
4. As a result of this session, I can identify similarities between parents and professionals.	1	2	3	4	5
5. During this session, I explored possible parent-professional differences.	1	2	3	4	5
6. The material presented was sensitive to all cultural groups.	1	2	3	4	5
7. The material covered information which was appropriate to all handicapping conditions.	1	2	3	4	5
8. The material presented matched my needs.	1	2	3	4	5
9. I will use some of the information/ resources that were introduced.	1	2	3	4	5
10. The instructors did a good job.	1	2	3	4	5

11. Specific suggestions to improve this module:

_____

_____

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